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ABSTRACT

This paper utilizes coordinated practice and research observations of the personal and familial accommodations made to disability of an adult member. No assets accrue from disability; a family has only those potentials it had earlier which may be abandoned or poorly used by a family in its coping endeavors, or utilized fully in making needed adjustments. The self-concept of a family need not be abandoned because of disability; in fact, a family may discover its central values and goals--a constructive rather than destructive process. The family as a social unit depends upon a range of supports to meet basic needs. Many of these resources exist within, and can be used to maintain the family as a unit. The disabled member must have a reciprocating function within the family even though he may have greatly altered capabilities, or the relationship will not endure. (Author/LAA)

REDEFINITION OF FAMILY STYLE IN RESPONSE TO THE REALITY OF A HANDICAPPED MEMBER*

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Recognition of the special needs of handicapped persons has grown much recently. Federal laws now stipulate that the design of new public buildings incorporate the elimination of architectural barriers. For many years, campaigns have been carried out from time to time asking employers to make room and work for the handicapped. In these endeavors, the implied rationale is that, if these sorts of allowances are made, the handicapped can then achieve equity with others.

It is the purpose of this paper to consider the impact upon the life-style of a family when one of its adult members experiences sudden disability that results in a handicapping condition. We shall examine the family as a human institution with human experiences and consider whether effective participation as an adult member in a family is impeded by personal handicap, and further, whether this reality makes qualification upon the life-style of the family.

In spite of sporadic publicity, literature, and presentations to the contrary, the family continues to be an essential element to the life of most people. (Ackerman, 1970) Granted that today's nuclear family sometimes proves unsatisfactory to its members and families are dissolved and re-formed, the purpose and activated alternatives are an attempt to provide for their members

those supports that have been provided historically by the family. These include identity, a central and favorable sense of self, and some system of reciprocal dependence. Alternative family styles hold some promise that the supplying of these needs will be on a more acceptable basis to the individual than that which he may have experienced earlier within his nuclear family. This has to do with the individual's willingness to make whatever personal contribution is required of him and his acceptance that the exchange is a favorable one. A common thread running through all of these alternate life-styles is the presence of a sustaining, and, on occasion, a healing potential. (Ackerman, 1971)

This potential is realized in many aspects of family and group living. The rock festival may provide for many the kind of reaffirmation of self, and kindred others that, in earlier times, was found through family reunions and community gatherings. These kinds of activities epitomize the resources available to the larger family for its members, for central to the treatment of the family as a unit, is the effort to assist troubled people to rediscover and mobilize latent forces from within which can serve to heal the hurt and relieve the pains of living that may have been inflicted upon its members.

The life-style of any family is the product of many forces. These include historical familial influences which each person brings to the family which he creates; also included are the values

and preferences that each individual has developed through his total living experiences. A synthesis of these forces occurs and leads to the life-style of the new family. As a unit, and through its members, that family continues to receive and to consider new data which may enhance its style of life. To an extent, the willingness of a family to consider new input to its life-style is a major determinant of the character of that family.

Some inputs have the potential of drastic change. A sharp rise in economic resources of the family is usually viewed as a positive force. Similarly, a sharp reduction in economic resources might be viewed as negative. We know, empirically, that a specific event does not have a predictable and uniform effect upon a family's life-style; indeed, the life-style includes a repertoire of characteristic responses to a range of circumstances from the most fortunate event to the most adverse.

Disability is neither sought nor planned for by anyone. When it occurs, it is usually without forewarning and with an immediate, shocking effect. It threatens the realizations of the afflicted individual, and by extension, the aspirations, and even the substance of the family. For the individual, this sudden traumatic event or illness breaks the thread of continuity in his life. The rational progression of his life by which he has moved toward self-fulfillment is halted. For the parent, the impact is heightened because his personal goals in life have been linked to his

contribution to and participation in his family. Because the handicapped individual may have been stripped of many of his abilities, ranging from self-care to earning a living, a prominent reaction can be one of despair and panic regarding the future of his family. (Gibson & Ludwig)

Rather than there being a uniform pattern of reaction to disability among those who are affected, it is suggested that the response of an individual and his family is more likely to be consistent with the stances they have developed through their own history in order to deal with adverse circumstances.

This is not to suggest that there are those families which maintain such equanimity in the face of adversity that they respond immediately and effectively; and, in polar fashion, that there are those families who fail continuously to make a constructive response. Rather, every family will be stunned initially by knowledge of the disability; however, most of them will begin quite early to utilize some characteristic means of coping with adversity. To this extent, family style becomes more a determinant of their accommodation to disability than it is vulnerable to abridgement or abandonment because of the disability.

One of the tasks that confronts professionals who are concerned with neutralizing and limiting the unfavorable aftermath of a catastrophic experience is the accumulation and refinement of

of knowledge that bears on such experience. We must continue to develop strategies and skills of intervention that can increase the number of families that are able to move beyond the social and emotional paralysis which they experience initially so that they are free to move to more productive accommodations to the realistic and harsh demands that have been added by the disabling event. In minimizing the crippling effects, we free the disabled person and his family from the confines of his handicap in a manner of spirit and attitude that is born from their sense of unity as a family. Central themes which guide us in this matter are the mutual love and preferences that the family members feel for each other.

Earlier, it was mentioned that disability is usually responded to consistent with the family's stance when dealing with adverse circumstances. Permanent or chronic disability provides a circumstance for constant testing of the members of the family. As in any testing, some pass and some fail. This situation of permanent disability is different from the usual sick role which has been well described for some time. (Mechanic)

The new situation requires that the disability must be accepted, and that life from now on will take place within greatly redefined parameters. Some disabled persons refuse to accept the realities of their limitations and attempt to insist that they have no limitations since, to admit this would be linked to an admission of personal worthlessness. In either extreme, the disabled one is

ill-equipped to work with his family towards a positive, viable restructuring process which will include him.

We note too that failures are not limited to the disabled person. Sometimes, the unafflicted partner is unwilling or unable to accept the restructuring that is dictated by circumstances. The altering and return of investment is not acceptable to such a person and he absents himself from the situation, often very early. In other situations, the person may be unable to carry out the new functions that are a matter of survival for the disabled person. This is not from lack of willingness, but lack of capacity. Such a person flees the situation in a move towards self-preservation. Here, we believe that only if such a person has requested it, should there be any therapeutic endeavor to help him to reverse the processes of disengagement that are taking place. Usually, the decision to leave has already been made.

It is of paramount importance that the disabled person be assisted in working through his feelings of abandonment. He must keep a positive notion of himself. He needs to free himself of feelings of bitterness and recrimination towards the person who has left, for they will interfere with his optimum recovery. A person who has been abandoned needs to restructure his life. This requires constructive attitudes and activities. If therapeutic intervention can free him from the constrictions of having been wronged, he is more able to address himself to this task.

Any substantial review of the literature relating to the experience of disability reveals that most attention has been directed to the response of families in which the handicap occurs in one of its children. (Brown) Much less inquiry has been made of the effects upon the child in the event of chronic disability in one of the parents. Among the reasons for this must be the established dependence of the child upon his family. (Boone & Harman)

Much of the response by professionals to the family's concern with the handicapped child can be related to the less well-defined needs of the family when the disabled member is one of the parents. A point of origination is the general acceptance of the view that the unit to be treated is the total family, not solely the specific patient. (Brodsky & Kaplan)

Another essential is the orientation that every member of the family has needs that rightfully should be met within the family. It should also be accepted that there is no rigid hierarchy of needs, but that all members have reason to expect that the family will provide as well as receive.

When families are beset with fate-altering events, such as the aftermath of disability, they sometimes become immobilized by the sudden changes in needs and resources. When treating such a family, the therapist may find as a major function the task of helping all members clarify and redefine the ways and

purposes for which they can depend upon one another. They need to regain an adequate sense of unity, and this draws heavily upon the family's experiencing a common spirit and identity. Perhaps this will necessitate the therapist assuming an advocate role in behalf of one family member until others alter their stance, and the reasonable needs of the neglected one become again a matter of active concern of all. This kind of approach is based upon the presumption that every member has some capacity to be concerned about the others, and also have concern with the family as a unit. Experience will show that this assumption can be made even of very young members of a family. Repeatedly, it will be found that a major task of family therapy is to improve the facility and accuracy with which members communicate among themselves. Families are helped toward a more favorable self-concept, toward family qua family. (Tallman)

This calls forth an improved sense of group. In working with families of schizophrenics, it has been found that very often, central to the distortions of the family, are some elements of family interrelationships, the nature of which serves to obscure defects in the family's ability to perceive and accept reality as it is perceived by those around them in the larger world. (Artiss)

Similarly, a family beset by the handicapping of one of the parents may have difficulty in determining the reality within which the family is to maintain a life-style. This task is made more

difficult by the insidiousness by which change may have occurred following the initial disabling event. Because it is nearly impossible to pinpoint the time of optimum recovery, we may find an underlying, even ill-concealed inaction, as the family waits for the disabled person to "get well." As time passes, there is less and less clarity as to just what getting well means, and, this often becomes an outward expression of acute anxiety with regard to the former patient's condition. This calls attention to the fact that very little in the way of therapeutic follow up is done for the family of the disabled adult, perhaps due to the insidiousness of change. This is in contrast, we believe, to the more accepted treatment of children who are disabled. Treatment and family involvement here are an ongoing, continuous process as the child struggles toward maturation. A specific plan, very often, is laid out for the family whereby they may transfer from agency to agency through the years as the needs of the child change.

It is suggested here that more attention should be paid to the family of the disabled adult. As time passes, pain within the family that they cannot define may be increasing. This is true particularly when gradual change for the worse has taken place for the patient. The family should have continuous access to the therapist who has some knowledge of what the style of life of the family had been prior to the disability. With this knowledge, assistance can be directed towards helping the family maintain as

much as possible of what they had earlier. It is not the task of the therapist to overhaul the family and make it what it never had the potential of being, but it would be helpful for the therapist to share what he sees within the family and to help correct factual errors. With verbalized descriptions of themselves, their hopes and dreams, their problems, realistic goals can be set, ones that are attainable. More often the intervention offered is that of short duration, with a focus upon immediate goals. Within this context, everything possible should be done to help the family weather the immediate crisis, help them resume their characteristic identity, and assist with restoring the self-sufficiency of the family as a unit. (Shellhase)

As medical advances assure us that more disabled persons do come home, their longevity extended, there are few families who are not in some way affected. Who among us does not know someone who is disabled -- he may be your neighbor, your co-worker, your friend, your relative, or your very own. Thus, we need to look more and more toward the development of community resources and a continuity of services available, not only to the handicapped, but to the family as well. (Nau) With our help, more and more disabled persons are able to live independent, fulfilled lives. We know that adversity, in whatever form, is not an ennobling experience. Rather, it is a rigid testing of individuals and their families. Having mastered the challenge, their reward is not a

trouble-free future; they are free instead to address the next challenge. A measure of success may be found within the extent to which all or most members of a family are able to realize their own personal aspirations, and to do so with a feeling that their membership in the family was an asset in this quest.

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